



## Increasing HIV/AIDS Therapy Adherence among Youth in Mozambique: The TAP/Pathfinder International Experience

### PATHFINDER INTERNATIONAL

Pathfinder International places reproductive health services at the center of our work around the world, providing women, men, and adolescents access to quality health services—from contraception, to maternal and newborn care, safe abortion services, and prevention and care of sexually transmitted infections and HIV/AIDS. We advocate internationally for sound reproductive health policies, seeking to improve the rights and lives of the people we serve.

The AIDS epidemic in Mozambique has reached crisis proportions. Adult prevalence is estimated at 16 percent (ages 15-49) and 14.4 percent among youth (ages 15-24). But these figures soar to 26 and 27 percent in Maputo and Gaza provinces; 60 percent of new cases occur among people under the age of 25.<sup>1</sup> Young women between the ages of 15-24 are 2.5 times more likely to become infected than males.

The average age of sexual debut in Mozambique is 16 years for females and 17 years for males. As of 2007, approximately 24 percent of eligible Mozambicans were receiving antiretroviral therapy (ART), but only 10 percent of these users are youth.<sup>2</sup> The number of clients of all ages who drop out of ART treatment is poorly tracked, and estimates range widely from 10 percent<sup>3</sup> to 25 percent,<sup>4</sup> reaching 37 percent in some sites.<sup>5</sup> In 2007 only 29.8 percent of HIV-positive

pregnant women received ART to reduce mother-to-child transmission.<sup>6</sup> While the importance of condom use to prevent HIV is nearly universally recognized, actual use remains a challenge and females are in a poor position to negotiate use. Young people have little access to information on sexuality, abortion, contraception, and HIV/AIDS, so myths and harmful practices are common.

<sup>1</sup> Ronda Epidemiológica, 2007, MOH/CDC. (Mozambique 2008 Progress Report for United Nations General Assembly Special Session on HIV/AIDS, (UNGASS). pp. 10-11).

<sup>2</sup> Ibid.

<sup>3</sup> Marazzi et al, "Improving adherence to highly active anti-retroviral therapy in Africa: the DREAM programme in Mozambique," Health Education Research, Vol.21 no.12006.

<sup>4</sup> Lio et al (2008). "Evaluating Adherence to Highly Active Antiretroviral Therapy with Use of Pill Counts and Viral Load Measurement in the Drug Resources Enhancement against AIDS and Malnutrition Program in Mozambique," *Clinical Infectious Diseases*; 46: 1609-1616.

<sup>5</sup> MOH information according to differences observed in the number of cases reported by clinics and patients taking ART drugs.

<sup>6</sup> UNGASS Report 2008, p. 9, p. 15.

## The TAP/PI Project

In 2004, the World Bank launched a pilot HIV/AIDS Treatment Acceleration Project (TAP) in Mozambique, Burkina Faso, and Ghana aimed at slowing the epidemic by increasing access to voluntary testing and counseling (VCT) and adherence to care and treatment. In Mozambique, the four-year US \$1.25 million TAP/Pathfinder International Project (TAP/PI) expanded on the successes of Pathfinder's nation-wide Geração Biz Program (GBP) (see callout). Technical and financial support was received from UNFPA, as well as advice and implementation by the ministries of Youth and Sports and Health and Education, and other youth associations.

### The Geração Biz Program

In 1999, UNFPA, Pathfinder International, and the Danish International Development Agency (DANIDA) collaborated with the Mozambique Ministries of Health, Education, and Youth and Sports to launch a comprehensive program focused on the sexual and reproductive health (RH) needs of youth. The *Geração Biz Program* (GBP) (“Busy Generation”) has since been heralded as an international best practice by the World Bank for providing in-depth sensitization of youth on RH, STIs/HIV/AIDS and for improving their behaviors and use of services.

By the end of 2007, GBP had expanded to all 11 provinces of Mozambique, establishing youth-friendly services (YFS) in 203 public health facilities. Nurses, medical assistants, and doctors have been trained to provide a range of RH and HIV services, contraceptive counseling and methods, antenatal and postnatal care, postabortion care, and STI prevention and treatment; 264,000 youth visited YFS clinics for testing, counseling, and services in 2007. By 2007, GBP had trained more than 6,900 peer educators (PEs), who played a key role in reaching more than 1.3 million youth in schools, communities, and at YFS clinics. In that same year, GBP distributed almost 2 million free condoms to young people.

The GBP has dramatically demonstrated the capacity and impact of youth participation in working with their peers. The 2007 GBP *Time to Know Campaign* raises awareness among youth about the importance of voluntary counseling and testing. Hundreds of PE advocates and counselors in schools and community outreach activities spread GBP messages in the face of the burgeoning epidemic, which has increased youth seeking HIV testing by more than 100 percent (from an average of 475 to 1,178 per quarter). Positive messages emphasize empowerment: “It is time to know my HIV status, because there is now treatment for HIV.”

YFS clinics were renovated and enhanced for the project in the Hospital Central Maputo (HCM) in Maputo City and in Xai-Xai Provincial Hospital in Gaza Province. Mirroring GBP successes, the new project gave peer educators (PEs) major roles in outreach, education, and the promotion of VCT and healthy RH behaviors, as well as counseling for retention and treatment adherence. HIV-positive PEs, in particular, brought their experience and high level of commitment to the counseling process and became positive and inspiring role models.

### THE RISK OF LOSING YOUNG PEOPLE FROM THE MEDICAL SYSTEM

A positive diagnosis of HIV is an overwhelming emotional crisis, especially for an adolescent. Highly sensitive to peer values and opinions, youth can be poorly equipped to handle a personal crisis alone. High levels of stigma and discrimination against HIV and AIDS can cause panic or depression—particularly if HIV is seen as a death sentence. Overwhelming shame can precipitate denial, isolation, and refusal to accept a positive diagnosis, which promotes continued risky sexual behavior and further HIV transmission. Isolation is common for young women who discover their HIV status at the same time they learn they are pregnant.

Service barriers can block youth from seeking counseling, testing, and care. They may avoid seeking services for a sex-related problem, justifiably fearing provider judgment and condemnation. Those needing ART may be unable to follow a disciplined drug regimen and have little tolerance for the frequent side-effects of ART.

Access and adherence to medical care and ART can mean life or death. Early diagnosis can prompt a healthy diet and lifestyle, (including consistent use of condoms), that will bolster the immune system, suppress the level of the virus, and delay or prevent the onset of AIDS and need for ART. With a low viral load, the client is less contagious and will develop fewer opportunistic infections. Sicker clients require more hospitalization and medication.

# TAP/PI Steps in Outreach, Care, and Treatment

## PROJECT SITES

The youth-friendly site at Hospital Central Maputo (HCM) provided a comprehensive range of services, including adolescent and youth sexual and reproductive health (AYSRH), VCT, postabortion care (PAC) and abortion care, and integrated HIV/AIDS prevention and care. The YFS clinic in Xai-Xai Health Center provided AYSRH services, including contraception, counseling, antenatal care, family planning, and STI treatment. As part of a district hospital for Xai-Xai, the clinic was an important resource for many satellite cities and neighboring communities.

## YFS AND VCT SERVICES

Referrals to the HCM YFS clinic came from school counseling centers, youth outreach programs, and 16 satellite YFS clinics in the city. In Xai-Xai, most referrals came from youth associations. YFS clients were welcomed and registered by a receptionist; the need for privacy and confidentiality was carefully respected to avoid concern about stigma. A team of physicians and one psychologist were available for a couple of hours daily to provide AYSRH services and voluntary counseling and testing. The act of getting tested was applauded as a healthy behavior, as it exposed the client to information about sexuality and risky behavior (e.g., many youth do not consider anal or oral sex to be “real sex” or risky), and offered access to dual protection, condoms, and other contraceptives with lessons on their effective use. A negative HIV test result prompted counseling to encourage determination to remain free of the virus with consistent condom use and regular retesting. Clients who tested positive were referred to the TAP/PI program.

## INTERVENTIONS FOR CLIENT RETENTION

Results from an HIV test were available in 15 to 30 minutes. Following a positive diagnosis, a young client at either hospital received the following interventions on the same day as the diagnosis:



The waiting area at the Maputo Central Hospital YFS Clinic is constantly full of young people. Many learn of the clinic from counselors at school and in the community, and they come just to listen and learn from peer educators who lead discussions, show films, and answer questions on ASRH topics. A peer educator is available weekdays from 9 am to 5 pm to counsel and support those testing negative as well as positive.

PHOTO: Sarah Day

**Testing:** The initial testing nurse provided follow-up counseling, emphasizing hope and positive action. A CD4 blood test was taken to determine whether ART should be initiated, but a client had to wait two to four weeks for test results. Many youth could be lost during this waiting period, making it crucial to provide immediate support and counseling to keep the client connected to healthcare providers.

TABLE 1: STAFFING AT XAI-XAI AND MAPUTO CENTRAL HOSPITALS

STAFF	XAI-XAI PROVINCIAL HOSPITAL	HOSPITAL CENTRAL MAPUTO (HCM)
DOCTORS	5	5
PSYCHOLOGISTS	1	3 (in shifts)
NURSES	2	5
HIV POS./NEG. PEER EDUCATORS	65/90	66/119
MEDICAL ASSISTANT	1	0
COMMUNITY COORDINATOR	1	1
RECEPTIONIST	1	1
DATA ENTERING ASSISTANT	2	1

## The Importance of Youth-Friendly Services (YFS)

Where YFS are absent, many young people go without care. Clinical providers can be hostile and judgmental towards youth seeking help for a sex-related problem.

Increased sexual activity among youth has provided impetus for the development of YFS, where youth can be confident that a facility and its providers will offer privacy, confidentiality, and nonjudgmental care. Well-trained YFS staff can put young people at ease, which can considerably increase the likelihood of their getting treatment.

Where a YFS clinic is located within a larger hospital, youth receive RH and HIV services in one place, which improves their chances of accepting a medical regimen and allows providers to impart a comprehensive package of information about healthy behaviors.

**Medical care:** A doctor provided a thorough examination and care for additional conditions and opportunistic infections, engaging the client in decisions about ART and positive lifestyle changes. Pregnant HIV-positive women were linked with the PMTCT+ program to optimize their own health and prevent transmission of the virus to the baby.

**Counseling:** A psychologist provided additional counseling and promotion of a healthy lifestyle. Clients were asked to identify a family member or friend who could become a confidant in the early stages after diagnosis. Disclosure is one of the greatest hurdles, due to fears of rejection and condemnation.

**Peer Educators:** The client was immediately assigned to an HIV-positive PE, who provided “sheltering” through counseling and role modeling. (There are 65 HIV-positive PEs in Xai-Xai and 66 in Maputo.)

The PEs’ positive sero-status and willingness to disclose it were essential motivators for young clients, challenging the common belief that anyone with the virus is sick and dying. PEs offered proof that it is possible to live a healthy life with HIV, and disclosure is not devastating. PEs reinforced the importance of adherence, coupled with optimism. Initially, PE sheltering was optional for each client, but upon seeing a significant difference in treatment adherence between sheltered and unsheltered clients, Pathfinder made sheltering and home visits essential elements of client care.

**Home visits:** With permission, the PE accompanied the client home on that first day of diagnosis. Seeking anonymity, clients often provided false addresses upon registration, and this “recognition home visit” ensured continued client contact. During home visits, the PE noted evidence of enough food and clean water in the home, and the potential for support from family relationships. In weeks to come, if the client failed to keep medical appointments, had family conflicts or other problems, the PE home visit ensured continued support and guidance. Moral support was needed for a client first disclosing the illness. If the client became sick, the PE coached family members in provision of care and made sure the client received treatment. The PE became a reliable source of information for the family and discouraged adoption of harmful diets and ineffective traditional treatments.

**Support groups:** All HIV-positive clients were urged to join a weekly youth support group at the YFS where they shared problems, exchanged ideas and advice, and consulted a psychologist or doctor about physical symptoms or problems with family, school, work, pregnancy, and other issues. For many, the group was a dress rehearsal to prepare for disclosure to family and friends.

## TRAINING

**Healthcare providers:** Between 2005 and 2009, seven nurses, ten doctors, four psychologists, and one medical assistant at HCM and Xai-Xai received a minimum of 80 hours of training in YFS, including stages of adolescence, how to communicate with youth, prevention and treatment of STIs, HIV/AIDS, and gender concerns. Technical follow-up and supervision ensured their full comprehension and use of the trainings. TAP/PI program staff developed a manual for trainers, a manual for providers, and a curriculum and guidelines on implementing YFS with VCT. More than 80 health providers were trained and related services were expanded to 38 additional YFS sites around the country.

**Peer Educators:** A total of 340 PEs were trained by Pathfinder in two phases, the first lasting 10 days. The Pathfinder training manual, *Community Home-Based Care for People and Communities Affected by HIV/AIDS*, was adapted to the Mozambique context and made to include home visits. An initial classroom portion covered



**Left:** Ana Langa (L) was very sick with AIDS when she went for testing. After many hospital stays, she was near death in her home. Alarmed by her condition, her PE, Rute, insisted that the doctor come to Ana’s home. He rushed her back to the hospital, where she was diagnosed with TB. With proper medication, Ana has now recovered. She and her mother (R) maintain that only Rute’s determined pleas with the doctors saved Ana’s life.

**Right:** Discouraged by the side effects of the medicines, Lionel stopped taking this ART and withdrew. Clarencita, his PE, became alarmed as he became sicker and sicker. When he was too weak to walk and could barely eat, she finally got him to the hospital for care and medication. “Without her, I would be dead,” confesses Leonel.

PHOTOS: Jennifer Wilder/Pathfinder International

AYSRH, contraception, and STIs/HIV/AIDS (with details on transmission, prevention, and the protocols for ART and PMTCT+). Instruction in counseling and listening skills, how to conduct home visits, and how to address the causes of stigma was followed with role playing and experience sharing.

Classroom instruction was followed by field experience. PEs observed one another in counseling sessions (with client permission), providing feedback on listening and

responding skills, as well as knowledge of the material. Phase II involved weekly supervision by community coordinators with support from MOH staff.

## Project Results

Epidemiological studies were conducted in collaboration with ICAP/Columbia University, using their Patient Tracking System. Table 2 on the following page shows the numbers of clients served at HCM and Xai-Xai YFS clinics between 2005 and 2008. The project began in March in Maputo and in November in Xai-Xai. A total of 6,542 clients were tested at HCM, and 5,699 were tested at Xai-Xai. Over the time of the project, 210 clients received ART at HCM and 446 clients at Xai-Xai.

Early rates of client deaths were higher in Xai-Xai as clients tended to be sicker at the time of first contact than later in the project, when larger numbers were tested before symptoms emerged.

Table 3 details the cumulative drop-out rate at HCM and Xai-Xai over the course of the project. It shows that, out of the 19 new ART clients in 2005 (from Table 2), none dropped out until 2008, when 3 left.

### “Sheltering” in the TAP/PI Project

Within the TAP/PI Project, “sheltering” is a package of interventions essential to engaging and maintaining a young person newly-diagnosed with HIV. HIV-positive PEs and providers move to protect and support the young person, virtually surrounding him or her with counseling, mentoring, medical interventions, and friendship to stave off despair and ensure adherence to necessary medical regimens.

And in 2007, the ART program received 59 new clients, which made a total of 133 active clients. Of the 59 new clients in 2007, 3 dropped out in that first year and another 8 in 2008 for a cumulative total of 11. Thus, the total cumulative number of drop-outs was 24 for HCM, for a rate of 11.4 percent. The cumulative rate in Xai-Xai was 16.1 percent.

These figures demonstrate highly successful adherence retention rates for young clients during the first months—and even years—of their diagnosis with AIDS, which is the phase where they are most vulnerable and apt to drop out. Further data is needed to determine whether

these later losses were due to actual dropping out of treatment or moving on to a different community (hopefully staying in treatment). In the third quarter of 2007, the Xai-Xai figures are skewed by a significant increase in losses when the acting health minister directed health centers, like the YFS in Xai-Xai, to instruct ART patients to access their medication through general pharmacies. These extremely crowded facilities, where confidentiality is nonexistent, lack all of the benefits of YFS. The rate of client loss in terms of both deaths and voluntary drop-outs jumped drastically. Four to six weeks later, the direction was rescinded and the rate of client loss returned immediately to its former level.

**TABLE 2: PROJECT RESULTS BY PROJECT SITE AND YEAR (ANNUAL TOTALS)**

	HCM					XAI-XAI				
	MAR 2005	2006	2007	2008	TOTAL	NOV 2005	2006	2007	2008	TOTAL
VCT CLIENTS	1,226	1,303	1,699	2,134	6,542	184	610	2,093	2,812	5,699
NEW HIV CASES	89	243	301	299	932	114	451	826	671	2,062
% OF VCT CLIENTS FOUND TO BE HIV+	7%	74%	19%	73%	—	18%	40%	14%	24%	—
# ART CLIENTS (INDIVIDUALS)	19	55	59	77	210	—	81	206	159	446
% OF HIV POSITIVE CLIENTS RECEIVING ART*	21%	23%	23%	18%	—	20%	25%	25%	24%	—
# CLIENT DEATHS	2	3	11	2	18	1	9	11	3	24
PMTCT CLIENT VISITS**	—	44	77	55	176	—	132	199	398	729
ART CLIENT VISITS	—	457	529	604	1,590	—	485	2,494	2,691	5,670
NON-ART VISITS	—	456	820	787	2,063	—	681	1,694	2,140	4,515
OPPORTUNISTIC INFECTION TREATMENT VISITS	—	72	142	96	310	—	175	334	310	819
HOME-BASED VISITS	—	82	538	848	1,468	—	73	986	1,258	2,317

\* The percentage of people who need ART is actually higher than those who receive it.

\*\* These components had not yet begun in 2005.

**TABLE 3: CUMULATIVE DROP-OUT NUMBERS AND RATE**

Year of Entry	# ART Clients	HCM					Year of Entry	# ART Clients	XAI-XAI				
		Drop outs per year							Drop outs per year				
		2005	2006	2007	2008	TOTAL			2005	2006	2007	2008	TOTAL
2005	19	0	0	0	3	3	2005	—	0	1	1	3	5
2006	55	—	0	2	7	9	2006	81	—	9	6	3	18
2007	59	—	—	3	8	11	2007	206	—	—	35	8	43
2008	77	—	—	—	1	1	2008	159	—	—	—	6	6
TOTAL DROP OUT		0	0	5	19	24	TOTAL DROP OUT		0	10	42	20	72
CUMULATIVE # OF ACTIVE CLIENTS USING ART		19	74	133	145	—	CUMULATIVE # OF ACTIVE CLIENTS USING ART		0	81	277	394	—
% ACTIVE DROP OUTS		0.0	0.0	3.8	13.1	11.4	% ACTIVE DROP OUTS		0	12.3	15.2	5.1	16.1

Compared to the estimated 10-37 percent national client losses noted earlier, loss rates of 11.4 percent for HCM and 16.1 percent for Xai-Xai were significant, particularly given the age of the client population. This shows a high degree of success in meeting both targets for the TAP/PI Project: convincing more youth to seek VCT and retaining those who are HIV-positive in the care system. Both sites showed a steady increase in numbers of VCT clients due to large networks of PEs (and referral facilities in Maputo). Xai-Xai's higher number of positive new cases reflects the probability that those who sought testing were pursuing more risky behavior. Overall numbers are lower at HCM because it is only one of several YFS clinics in Maputo providing testing.

## Lessons Learned

Many lessons have emerged from the TAP/PI Project related to programmatic approaches and the complementary roles of healthcare providers linked with youth peer educators.

### THE IMPORTANCE OF PEER EDUCATORS

Well-trained and committed peer educators—especially those who are HIV-positive—offer great promise for future programming. Their successful approach to living with HIV make every lesson learned of personal life-saving importance. Their optimism and eagerness to share their knowledge are enhanced by recognizing how much their sero-status contributes to their credibility and power to motivate and implant hope.

Pathfinder deliberately gave the PEs increasing responsibility and latitude in planning and organizing their community outreach activities. Their independent exploration of ideas and approaches allowed them to develop strategies and interventions appropriate to their communities. Personal successes were frequently compounded, as many became competent community leaders in their own right, pursued by programs to staff new projects.

The significant power of “sheltering” activities reinforces the importance of PEs. Support group membership served as an anchor for many clients. Peer educators universally agree that home visits were crucial to maintaining contact with adolescents, many of whom are inclined to run away from the HIV diagnosis and its

burdens. As the number of recognition home visits increased from 45 percent to 83 percent of all cases, far fewer clients disappeared.

Many HIV-positive PEs were deeply affected when first visiting someone sick with AIDS. These sobering visits reinforced their determination to live healthy lives and redouble their efforts to encourage others to practice prevention and personal care.

The integration of PEs into clinics prompted an unforeseen outcome for the program. Their enthusiasm and high quality service gave healthcare providers insight into the value of youth-friendly services. They could see how standard medical procedures might be experienced as derogatory and rejecting. Through relationships with PEs, providers learned how to make their services more client-centered, recognizing this as a major improvement to quality care and impact.

### Inhambane Province: Unfunded Replication of Best Practices

Health officials in Inhambane Province have replicated TAP programming without outside funding by introducing VCT and ART in nine YFS clinics. Two additional clinics in the province of Gaza have also started offering ART for youth, and six HIV-positive PEs have been trained to conduct home visits in collaboration with those clinics.

While the psychologists in both clinics played important roles in counseling clients and mentoring counseling staff, few of them exist in Mozambique, and efforts to replicate this project in more remote areas will necessarily not include them. They contributed significantly to support group success, providing guidance on everything from group facilitation to management of medical problems. However, well-trained and competent PEs can be trained as group leaders, offering the much-needed mini-communities that these groups provide for isolated youth. Mechanisms must be developed to enable resource-weak communities to develop their own PEs, nurture them with information and distance learning, and help them to educate youth about testing, safe and healthy living with HIV, and condom use as a responsible necessity. Trained PEs could also provide VCT to remote communities.



“At the support group you learn about many things that are going on—or will go on—in your body, that no doctor has time to discuss. And you take their advice, because you are hearing it from people who speak from experience. Without the group, many people would leave the YFS without a lot of important information. The PE is a complimentary source of information and emotional support.”

**SERGIO JOSÉ MAHUMANE, A PEER EDUCATOR WHO LEADS THE HIV SUPPORT GROUP**

PHOTO: Sarah Day

Lay counselors have provided effective counseling and mentoring in several countries, and could become a model for replication here. Dr. Carla Pelaye, Chief Provincial Medical Officer in Gaza Province, seeks to expand the number of YFS clinics embedded in health units in Gaza from the current 22 to all 121 units. She wants to train HIV-positive PEs to work with and train lay counselors within communities, drawing on the credibility and influence of community and religious leaders. The lay counselors would also be trained to provide VCT in remote and hard-to-reach parts of the province.

## CLINICAL ESSENTIALS

As detailed above, quality youth-friendly services, staffed by highly-trained and committed staff, are key to attracting and retaining youth in a medical program—particularly one as stigmatized as HIV/AIDS.

As it became known in the community that ART was always available through the TAP/PI program, and that it really did offer hope to people with the virus, more youth began to seek testing and condoms. VCT requests by boys went from 13 percent before the program to 45 percent in 2007 at one clinic. Access to and information about ART can stimulate widespread preventive behavior, as the expectation of healthy treatment can override fear of receiving a positive diagnosis.

Given the high incidence of HIV among young women, all programming must provide PMTCT+, including contraception counseling and prevention of vertical transmission to a baby.

## VALUE ADDED FROM GERAÇÃO BIZ PROJECT

The dynamic presence of the Geração Biz Project provided TAP/PI with enormous momentum from its launch, and the two projects soon mutually reinforced one another. The widespread and highly effective *Time to Know Campaign* made a major difference in motivating and enabling youth to come into the YFS clinics to explore questions about sexuality and HIV. Without this access to youth, TAP/PI would have had far less impact, given low levels of knowledge and the deep cultural barriers to learning about sexuality and RH. The GBP has given youth permission and space to talk about these issues and has paved the way for their seeking help, information, and services.

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